European Journal of Oncology Nursing 16 (2012) 145–152

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

Self-perceived burden in patients with cancer: Scale development and descriptive study

Miki Oeki [a,*], Tamiko Mogami [b], Hiroshi Hagino [a]

[a] *Department of Fundamental Nursing, Faculty of Medicine, Tottori University, 86 Nishi-cho, Yonago city, Tottori 683-8503, Japan*
[b] *Clinical Psychology, Graduate School of Medical Sciences, Tottori University, Japan*

Keywords:
Self-perceived burden
Cancer patient
Scale development
Quality of life

A B S T R A C T

Purpose: The purpose of this study was to develop a Japanese version of the Self-Perceived Burden Scale (SPBS) for patients with cancer, to confirm its validity and reliability, and to elucidate the features of Self-Perceived Burden in Japanese patients with cancer.
Methods: Firstly, study team members carried out repeated translation and back translation. After that, scale development involved several phases including item development, construct validity testing, criterion-related validity testing, and reliability testing. A questionnaire that included the SPBS was distributed to 310 patients with cancer. Responses were received from 226 (72.9%) patients and final analysis was performed on data from 210 of these.
Results: Exploratory factor analysis indicated that the 18-item version ($\alpha = 0.96$) of the scale consisted of a single main factor. A 9-item abbreviation ($\alpha = 0.93$) was therefore proposed. The convergent correlations of the SPBS with the FACIT-Sp and GHQ-12 scales showed significant correspondence. The construct of SPB was distinct from the "social and family well-being" FACIT-Sp subscale. Performance status, disease duration, living arrangement, and main caregiver were significantly related to the SPBS.
Conclusion: We developed a Japanese version of the SPBS for cancer patients and demonstrated its validity and reliability, which makes it possible to study SPB in cancer patients in Japan. Our study revealed that cancer patients in Japan also feel SPB, in a way that relates specifically to their cultural background.

Introduction

With the worldwide proportion of the elderly rising, the number of cancer cases and cancer-related deaths continue to increase. It is well known that the suffering caused by cancer has a profound effect on the daily lives of patients and their families. Patients regularly rely on family and friends for emotional and instrumental support to meet the demands of the illness (Zabora et al., 2001). In other areas of health, such as renal disease, it is evident that receiving care can for some people lead to the sense of having become “a burden to others”. This sense of burden, or what Cousineau et al. (Cousineau et al., 2003) referred to as “self-perceived burden” (SPB), is important because it can influence exchanges within caregiving relationships and also affect how people adapt to the functional and psychosocial changes brought about by their disability.

SPB is defined as “empathic concern engendered from the impact on others of one’s illness and care needs, resulting in guilt, distress, feelings of responsibility, and diminished sense of self” (Cousineau et al., 2003). Wilson et al. found that SPB was mentioned by 59% of people with advanced cancer who expressed an interest in hastened death (Wilson et al., 2007). A consistent finding is that cancer patients’ perception of SPB is a significant factor in their quality of life (QOL) (Cohen and Leis, 2002; Wilson et al., 2005; McPherson et al., 2007; Simmons, 2007). Gilbar interviewed elderly, married, male cancer patients. He found that these patients worried about the size of the burden they were placing on their spouses, and this worry affected their decisions about palliative care (Gilbar, 1994). Importantly, participants with higher levels of SPB were less likely to seek help from others (Cousineau et al., 2003). Few studies, however, have focused directly on the issue of SPB, with most relevant research addressing other topics and including SPB only as a secondary consideration. Despite existing qualitative evidence that SPB experienced by cancer patients affects QOL, only a few reports are available which

---

* Corresponding author.
E-mail address: ooeki@med.tottori-u.ac.jp (M. Oeki).

1462-3889/$ – see front matter © 2011 Elsevier Ltd. All rights reserved.
doi:10.1016/j.ejon.2011.04.010

use a quantitative self-report instrument to assess cancer patients' SPB (McPherson et al., 2007; Simmons, 2007).

Cousineau et al. (Cousineau et al., 2003) define SPB as a multifaceted concept in which a care-recipient initially experiences frustration and worry as a result of feeling dependent on their caregiver, which then leads to guilt over the degree to which the caregiver is negatively affected in the areas of physical health, emotional and mental health, and financial well-being. To develop the scale items for the SPB Scale (SPBS), the group derived 25 statements from the literature on caregiver burden and from interviews with dialysis patients about their experiences of burden (Cousineau et al., 2003). An abbreviated version of the SPBS has been also developed, consisting of 10 items. The scale also has been used in studies of people with amyotrophic lateral sclerosis (ALS) and stroke (Chio et al., 2005; McPherson et al., 2010), and its validity and reliability have been confirmed.

The SPB might differ among geographical areas, since cultures can vary substantially. At the time of this writing, no instrument that specifically assessed the SPB of cancer patients existed in Japan. The validation of such a tool was therefore seen as the first step to identifying an instrument that would be useful in both cancer care and research. We considered that adapting the SPBS to Japanese patients with cancer would make it possible to elucidate the features of SPB based on a culture that differs significantly from those of Western countries.

The purpose of this study was to develop a Japanese version of the SPBS for patients with cancer, to confirm its validity and reliability, and to elucidate the features of SPB in Japanese patients with cancer.

Methods

Study design

The current study consists of scale development by translation and descriptive study.

Participants and data collection

Participants with cancer were recruited from the outpatient populations of 12 public hospitals and local clinics in the western region of Japan. A survey method was used to collect data from July through December, 2009. The clinical inclusion criterion was a solid carcinoma of any stage (TNM classification) regardless of performance in activities of daily living. Recurrent cancer cases were included, but patients in whom carcinomas were excised completely were excluded. Leukemia, lymphoma, and other hematogenic malignancies were excluded. Inpatients at the time of investigation were excluded. Patients were eligible to participate in the study if they were at least 20 years old, the duration between their first visit to the hospital and the beginning of the study was longer than one month, and they had no severe mental disorders or dementia.

Sociodemographic and clinical variables

Participants completed a demographic profile that included information on (a) gender; (b) age; (c) employed status; (d) marital status; (e) type of cancer; (f) performance status (the Eastern Cooperative Oncology Group Performance Status: ECOG-PS); (g) disease duration; (h) treatment of the carcinoma; (i) complications; (j) living arrangement (with spouse and children, with spouse and parents, with children and parents, with spouse, alone); (k) main caregiver; (l) gender of main caregiver; (m) age of main caregiver; (n) employment status of main caregiver.

Instruments

Self-Perceived Burden Scale (SPBS)

The SPBS (Cousineau et al., 2003) is a 25-item (Table 1) self-report measure that uses a 5-point Likert scale to indicate the degree of self-perceived burden experienced. Higher scores indicate greater perceived burden. Likert-type responses range from "none of the time" to "all of the time." Respondents are instructed to think about the person who helps them with day-to-day activities such as shopping for groceries, getting medicine, preparing meals, and transporting them to the hospital, and to answer the questions about that person. The instructions explicitly directed the subject to include only people who are not paid, such as friends, family members, or children. Cousineau preliminarily validated the SPBS with dialysis patients, finding a Cronbach alpha of 0.93 for the SPBS and 0.85 for the abbreviated version (Cousineau et al., 2003).

Functional Assessment of Chronic Illness Therapy-Spiritual (FACIT-Sp)

The FACIT-Sp scale was used to assess QOL and an additional self-rating scale on spirituality (Cella et al., 1993). The FACIT-Sp scale includes seven physical items, six social and family items, six emotional items, seven functional items (herein referred to as the FACT-General: FACT-G scale) and 12 spirituality items (herein referred to as the FACIT-Sp subscale) (Cella et al., 1993). Using these individual subscales, it is possible to evaluate overall QOL. A 5-point Likert scale is used for question responses, with choices ranging from "very much" to "not at all." Shimozuma translated the instrument into the Japanese language with the permission of the developer (Shimozuma, 2002). The reliability and validity of the Japanese language version of the FACIT-Sp was confirmed in a previous study (Noguchi et al., 2004). The FACIT-Sp was added to the SPBS questionnaire as the external criterion.

The General health Questionnaire-12 (GHQ-12)

The GHQ-12 was used to screen for general psychological morbidity and capture the construct of distress (Goldberg, 1978). The GHQ-12 is a self-rating questionnaire with 12 items (Goldberg and Williams, 1988). Each item is scored on a scale of increasing severity (0–4). The GHQ was added to SPBS questionnaire as an external criterion.

Translation of the SPBS into Japanese

In line with approaches to cross-cultural scale translation, three steps were taken (Vallerand et al., 1992). First, the scale was translated from English into Japanese by two bilingual individuals. This translation was then translated back into English by two different bilingual individuals without the use of the original scale. To the extent that the original scale was appropriately retranslated, this method provides an initial assessment of the adequacy of the translated version of the scale. In this study, four bilingual individuals (one linguist, two health professionals, and one psychologist) conducted the translation procedure.

In the second phase, the items were reviewed by the study team to assess face and content validity. These experts were asked to comment on the relevance, comprehensiveness, and importance of each item. In particular, Japanese are not familiar with the term "guilty," and it is difficult to express the phrase "too much trouble" in Japanese. Therefore, the study team decided to express these concepts using more general terms while maintaining the desired meanings.

In the final phase, the Japanese version of the SPBS was pretested with 10 Japanese patients (four males and six females, ranging from 24 to 70 years of age with a mean of age of 52.4 ± 16.7